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Ten Years after the Creation of the Portuguese National Network for Long-Term Care in 2006: Achievements and Challenges☆

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ABSTRACT

The Portuguese National Network for Long-term Integrated Care (*Rede Nacional de Cuidados Continuados*, RNCCI) was created in 2006 as a partnership between the Ministry of Health and the Ministry of Labour and Social Solidarity. The formal provision of care within the RNCCI is made up of non-profit and non-public institutions called Private Institutions of Social Solidarity, public institutions belonging to the National Health Service and for-profit-institutions. These institutions are organized by type of care in two main settings: (i) Home and Community-Based Services and (ii) four types of Nursing Homes to account for different care needs. This is the first study that assess the RNCCI reform in Portugal since 2006 and takes into account several core dimensions: coordination, ownership, organizational structure, financing system and main features, as well as the challenges ahead. Evidence suggests that despite providing universal access, Portuguese policy-makers face the following challenges: multiple sources of financing, the existence of several care settings and the sustained increase of admissions at the RNCCI, the dominance of institutionalization, the existence of waiting lists, regional asymmetries, the absence of a financing model based on dependence levels, or the difficulty to use the instrument of needs assessment for international comparison.

1. Policy background

The current demographic and epidemiological transition is posing more challenges in developed countries, namely due to the increasing percentage of elderly and changes in patients' morbidity (e.g. increase of chronic diseases with longer treatment times) [1]. With a rapidly ageing population, Portugal is not an exception. This situation has worsened due to the effects of the economic crisis, which resulted in the emigration of fertile and active citizens [2].

Conscious that the adoption of new policies to (re)configure the health and social care is essential to face these new challenges, several historical milestones and partnerships between the Ministry of Health (MoH) and the Ministry of Labour and Social Solidarity (MLSS) culminated in the formal creation of the current National Network for Long-term Integrated Care (*Rede Nacional de Cuidados Continuados Integrados*, RNCCI).

Based on already existing institutions, the RNCCI has, as its backbone, the non-profit and non-public institutions known as Private Institutions of Social Solidarity (*Instituições Particulares de Solidariedade Social*, IPSS) [3], with the *Misericórdias* (religious non-profit-making institutions with a charitable background) being the main providers [4,5]. Based on the work developed with the IPSS, and in line with the redefinition of long-term care (LTC) services in many European countries due to the increasing number of dependents (Table 1) [6–9], the RNCCI was launched in 2006 [10]. Since then, besides the IPSS and public institutions, a growing number of for-profit-institutions with protocols with the MoH have emerged to provide LTC.

This is the first time that information about the RNCCI has been collated and made available to an international audience, as well as analysed to provide a thorough assessment of its achievement while providing some guidance to policy-makers on potential improvements and future challenges.

2. Main features of the Portuguese LTC system

The RNCCI embraces all forms of continuous, rehabilitation, palliative and nursing care for people with mental and physical lim-

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Table 1
Main characteristics of the long-term care system in selected countries.

Countries	Beneficiaries	Coordination	Organizational structure	Needs assessment instrument	Financing system*	Beds per 1000 inhab. ≥ 65 years**	Individuals treated per 1000 inhab. ≥ 65 years (NH/HCBS)**
France	Dependent persons (mainly individuals aged ≥60 years)	Central government (National Solidarity Fund for Autonomy) and departments (*les Conseils généraux*).	Personalized allowance for autonomy (*Allocation personnalisée d'autonomie*, APA), households (*etablissements d'hebergement pour personnes agées*) and long term inpatient units (*unités de soins de longue durée*).	• Dimensions assessed: ability to perform ADL. • Instruments used: a) Individuals aged up to 60 years: *Guide d'évaluation des be-soins de compensation des personnes handi-capées* (GEVA) (no dependence levels); b) Individuals aged over 60 years: *Autonomie, Gérontologie, Groupe Isso Ressource* (AGGIR) (4 dependence levels).	• Public spending on LTC as% of GDP: 1.89% (20% via cash benefits, 80% in-kind). • LTC as a share of current healthcare expenditure: 17.1%.	53.1	n.a./n.a.
Germany	All insured persons depending on the extent of LTC needs, regardless the age	Central Association of Health Insurance Funds (*Spitzenverband*), Federal Association of LTC Insurance Funds (*Spitzenverband Bund der Pflegekassen*) and the Confederation of Municipal Authorities' Associations (*Bundesvereinigung der kommunalen Spitzenverbände*)	Home care (in-cash and in-kind), in day- or night-care institutions and nursing homes.	• Dimensions assessed: ability to perform ADL and IADL. • 4 dependence levels (I, II, III and hardship cases).	• Public spending on LTC as% of GDP: 1.91% (31% via cash benefits, 69% in-kind). • LTC as a share of current healthcare expenditure: 17.1%.	54.4	48.0/121.0
Italy	Dependent persons (mainly elderly)	Central government (*Istituto Nazionale Previdenza Sociale*), local health units (*aziende sanitarie locali*) and municipalities.	Community care, residential care and cash benefits.	The instrument used differs according to each region. Nevertheless, the multidimensional assessment is based on validated international standards.	• Public spending on LTC as% of GDP: 0.91% (42% via cash benefits, 58% in-kind). • LTC as a share of current healthcare expenditure: 10.1%.	18.5	34.4/68.2
Netherlands	Dependent persons (mainly elderly)	Exceptional Medical Expenses Act (*Algemene Wet Bijzondere Ziektekosten*), regional care offices (*zorgkantoren*) and municipalities.	Home care, nursing homes and cash benefits.	• Under responsibility of the Centre for Care Assessment (*Centrum Indicatiestelling Zorg*). • Dimensions assessed: somatic, psycho-geriatric, physical, sensory or intellectual handicap, psycho-social problems. • There are no levels of dependence.	• Public spending on LTC as% of GDP: 3.96%. • LTC as a share of current healthcare expenditure: 37.4%.	73.9	84.2/183.7

Table 1 (*Continued*)

Countries	Beneficiaries	Coordination	Organizational structure	Needs assessment instrument	Financing system*	Beds per 1000 inhab. ≥ 65 years**	Individuals treated per 1000 inhab. ≥ 65 years (NH/HCBS)**
Portugal	Dependent persons (mainly elderly)	Central government (MoH and the MLSS), regional (*Administrações Regionais de Saúde*) and local (*Agrupamentos de Centro de Saúde*).	Nursing Homes (Convalescence Units, Medium Term and Rehabilitation Units and Long-Term and Maintenance Units), palliative care (National Network of Palliative Care) and home care.	• Dimensions assessed: biological, psychological and social. • Instrument used: Integrated Bio-psychosocial Assessment Instrument. • 4 dependence levels (incapable, dependent, autonomous and independent).	• Public spending on LTC as% of GDP: 0.96% (1% via cash benefits, 99% in-kind). • LTC as a share of current healthcare expenditure: 10.7%.	4.03	15.1/9.1
Spain	Dependent persons (mainly elderly)	Central government, regional (*Comunidades Autónomas*) and local entities.	Tele-care, home care, personal care help, residential care and day/night residential services.	The instrument used differs according to each region. Nevertheless, the multidimensional assessment is based on validated international standards.	• Public spending on LTC as% of GDP: 0.90% (33% via cash benefits, 67% in-kind). • LTC as a share of current healthcare expenditure: 9.8%.	44.4	24.3/93.9
Sweden	Dependent persons (mainly elderly)	Regional authorities (*Skåne and Västra Götaland*), municipalities, county councils.	Home care, nursing homes, day activities, home nursing care, meal services, personal safety alarms and home adaptation.	The instrument used differs according to each region. Nevertheless, the multidimensional assessment is based on validated international standards.	• Public spending on LTC as% of GDP: 3.46% (4% via cash benefits, 96% in-kind). • LTC as a share of current healthcare expenditure: 31.5%.	65.5	60.8/175.7

Source: France [6,23], Germany [6,23], Italy [6,7,23], Netherlands [8,23], Portugal [7,23], Spain [6,7,23], Sweden [6,23].

Note: The comparative countries were selected based on its geographical and cultural proximity (Spain, France and Italy), as well as for the more experience and diversity of services provided (Germany, Sweden and the Netherlands).

ADL: Activities of daily living; IADL: Instrumental activities of daily living; n.a.: not available; MoH: Ministry of Health; MLSS: Ministry of Labour and Social Solidarity.

* Long-term care public expenditures, including both health and social components, in 2015 [29].

** includes both public and private beds except for Portugal where only beds paid by the NHS are considered, data from 2015 [29].

itations, who are unable to take care of themselves without some support [10]. The following section identifies the main pillars of the LTC in Portugal and, whenever possible, compare them to other countries.

2.1. Beneficiaries

Similar to several European LTC systems (Table 1), the RNCCI offers universal coverage for those in a situation of physical or cognitive impairment, or requiring continuous health monitoring and social support [10]. Despite all inhabitants being eligible for LTC, the existence of regional asymmetries in care coverage still poses an important barrier to access to LTC. According to recent estimates, 93% of the Portuguese population had poor access to institutionalized care in 2014, given the lack of beds available [11].

2.2. Coordination

As in several European countries (Table 1), the Portuguese LTC system is decentralized and hierarchized, being managed at three governmental levels [2,5,7]: i) Central, where the MoH develops the national health policy and monitors its implementation; ii) Regional, where the five Regional Health Administrations implement the national health policies goals and coordinate all levels of health care; and iii) Local, where the Primary Care Trusts are responsible for providing home care and refer patients to LTC.

2.3. Organizational structure

As for care provision, given the cultural proximity between countries and the large experience in the provision of LTC, the Portuguese public system of LTC is based on the Catalonian model (*CatSalut*) [12,13]. It is organized in two main settings of care: Home and Community-Based Services (HCBS) and Nursing Homes (NH) [10]. Human resources are not allocated according to patients' needs as in other European countries [6,7,9], but by the number of weekly hours of care a patient is entitled to receive from each professional category [14].

Regarding HCBS, the nursing, medical and rehabilitation care is provided at home between 8am to 8pm to people with functional dependence by teams working in primary care centres [15]. Individuals without a caregiver, in need of 24 h care or only social care are excluded. Initially there were four types of NH [10], i) Convalescence Units (*Unidades de Convalescença*, UC) provide medical, nursing and rehabilitation care on a daily basis to individuals with an expected maximum length of stay of 30 consecutive days; ii) Medium Term and Rehabilitation Units (*Unidades de Média Duração e Reabilitação*, UMDR) offer less intensive nursing and rehabilitation care, with an expected length of stay between 31 and 90 consecutive days; iii) Long-Term and Maintenance Units (*Unidades de Longa Duração e Manutenção*, ULDM) aimed at individuals with difficulties of community inclusion and caregivers' respite care, with an expected length of stay of 90 or more consecutive days; iv) Palliative Care Units (*Unidades de Cuidados Paliativos*, UCP) aimed to offer late stage and end-of-life care to patients with terminal illness. In 2015, these Units were included in the National Network of Palliative Care (*Rede Nacional de Cuidados Paliativos*) [16].

2.4. Needs assessment

The assessment of the burden of diseases, dependence level or social enrolment are typically used to rank the recipients of care and to ascertain the level of LTC needs. Thus, several countries have adopted different assessment methods [6], which may vary across regions (Table 1), with some using them for financial reimbursement purposes or to identify the complexity level of the individuals treated like Spain (Catalonia) [13] or Italy (Tuscany) [17]. In Portugal, there is only one tool to identify the dependence level of each individual: the Integrated Bio-psychosocial Assessment Instrument. It collects information in three domains [18]:

- Biological: age, gender, clinical conditions and physical status using the Katz Index of Independence in activities of daily living [19] (toileting, dressing, bathing, transferring/bed, transferring/chair, continence/urination, continence/defecation and feeding);
- Psychological: cognitive status using the Mini-Mental State Examination [20] (including the ability to answer questions about temporal and spatial orientation);
- Social: level of education, marital status and availability of informal support.

The responsibility for this assessment lies with hospitals if the individuals are hospitalized or primary care providers if they are living in the community. Then, based on the physical and cognitive scale used, patients are classified into one of four dependence levels [21]: i) incapable, when individual does not cooperate and needs indispensable and regular caregivers and/or means of support; ii) dependent, when individual cooperates but needs indispensable and regular caregivers and/or means of support; iii) autonomous, when individual cooperates but needs regular means (but not caregivers) of support; iv) independent when individual does not need caregivers and/or means of support. After determining the care needs, providers should refer them to the best setting of care after taking into account his/her dependence level, expected length of care need (in case of institutionalization care) and, whenever possible, proximity to their residence.

2.5. Financing system

The model adopted by the RNCCI encompasses several sources that complement each other [7,22]: i) public funding ensured by the State Budget and shared between the health and social sectors; ii) profits from social gambling and betting (e.g., national lottery) allocated to the MoH (16.6%) and to the MLSS (13.4%); and, iii) means tested co-payments. Although 80% and 20% of the LTC services among countries in the EU are in-kind and cash-benefits, in Portugal they reached 99.3% and 0.7%, respectively [23]. This difference is explained by the scarce resources for cash-benefits, especially during the economic crisis period which resulted in a cut of benefits for some allowances for dependent adults [24], but still ensured the provision of public LTC through in-kind services.

The price paid by the MoH and the MLSS depends on where the care is provided [10]. If it is at HCBS (9.58€ user/day), UC (105.46€ user/day) or UCP (105.46€ user/day), the payment is entirely supported by the MoH. If it is at UMDR (87.56€ user/day) or ULDM (60.19€ user/day), the payment is shared between the MoH (70% and 20%, respectively) and the MLSS (30% and 80%, respectively) [25]. In these last two types of NH, payment by care users is means tested based on a percentage of the annual average per capita wealth of all household members (including wages, bank deposits, financial assets, pensions, public housing allowances and social benefits but, excluding dependence disability allowances) for the part covered by the MLSS [26–28]. Although the amount supported by each individual is reviewed whenever there are changes in the household arrangement, it cannot exceed the price published for each Unit [27].

Table 2
The evolution of the main features of the RNCCI.

	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016
Nursing Home public beds										
Convalescence Units	423	530	625	682	906	867	860	860	764	811
Medium Term and Rehabilitation Units	646	922	1,253	1,497	1,747	1,820	1,895	2,021	2,306	2,578
Long-Term and Maintenance Units	684	1,325	1,942	2,286	2,752	3,031	3,692	4,094	4,411	4,723
Palliative Care Units	55	93	118	160	190	193	195	185	278	288
Total number of beds	1,808	2,870	3,938	4,625	5,595	5,911	6,642	7,160	7,759	8,400
Average number of beds per institution	17.4	19.3	20.8	21.2	21.9	22.1	22.4	22.7	23.1	23.3
Average number of patients treated per bed	3.3	4.7	5.3	5.6	5.8	4.5	4.3	4.4	4.0	3.9
Home and Community-Based Services										
Number of teams	37	72	96	214	253	243	267	274	286	279
Number of treatment places	n.a.	1,660	5,050	8,063	7,332	7,183	7,053	6,766	6,585	6,264
Number of treatment places per team	n.a.	23.1	52.6	37.7	29.0	29.6	26.4	24.7	23.0	22.5
Beds and treatment places per 1000 inhab. ≥ 65 years										
Nursing Homes	1.10	1.58	2.13	2.45	2.91	3.03	3.35	3.55	3.78	4.03
Home and Community-Based Services	n.a.	0.92	2.74	4.28	3.81	3.68	3.56	3.36	3.21	3.00
TOTAL		2.50	4.87	6.73	6.72	6.72	6.92	6.91	7.00	7.03
Number of individuals treated*										
Nursing Homes	5,934	13,457	20,692	25,990	32,713	26,831	28,721	31,191	31,307	32,545
Home and Community-Based Services	n.a.	1,660	2,608	5,278	9,139	11,578	13,804	14,577	15,221	15,582
TOTAL	5,934	15,117	23,300	31,268	41,852	38,409	42,525	45,768	46,528	48,127
Number of individuals treated/1000 inhab. ≥ 65 years										
Nursing Homes	3.6	7.4	11.2	13.8	17.0	13.8	14.5	15.5	15.3	15.6
Home and Community-Based Services	n.a.	0.9	1.4	2.8	4.8	5.9	7.0	7.2	7.4	7.5
TOTAL	3.6	8.3	12.6	16.6	21.8	19.7	21.5	22.7	22.7	23.1
Long-term care expenditures (Euro, Millions, current prices)										
Ministry of Health	14.79	23.34	60.19	113.49	112.22	138.05	120.31	120.94	116.69	136.06
Ministry of Labour and Social Solidarity	2.24	9.70	14.85	19.57	25.21	26.46	27.70	31.76	34.86	36.37
TOTAL	17.03	33.03	75.04	133.05	137.43	164.50	148.00	152.71	151.55	172.44
As a share of gross domestic product (%)**	0.69	0.74	0.78	0.78	0.79	0.86	0.89	0.94	0.96	n.a.
As a share of current healthcare expenditure (%)**	7.6	7.9	7.9	7.9	8.3	9.2	9.9	10.4	10.7	n.a.

Source: Authors elaboration based on the national reports [30,32–35].
Legend: n.a.: not available.
* Includes individuals admitted in previous years who received some type of care in each year.
** Includes the expenditures of both long-term care public health and social components [29].

3. Development of the RNCCI since 2006

Despite the existence of regional asymmetries in LTC provision, the number of NH beds increased steadily over the years. The ULDM was the setting with the highest proportion of beds in 2016 (56%), followed by the UMDR (31%), UC (10%) and the UCP (3%) (Table 2). Considering both ratios of public beds/treatment places and individuals treated per 1000 inhabitants aged ≥ 65 years old, Portugal has also been showing a consistent growth over the years. However, despite the last indicator being lower than several European countries (Table 1), based on the latest national data available, the number of individuals waiting to be admitted at RNCCI has increased from 1,400 in 2016 [30] to 2,450 in 2017 (September) [31]. This shows an increase in referrals but also a lack of capacity to deal with current demand. Concerning the share of LTC public expenditures on GDP and health care expenditure, Portugal (Table 2) presents higher ratios than Spain or Italy (Table 1), even when undergoing a difficult financial and economic crisis.

Although the fully RNCCI implementation was planned to be concluded over a 10-year period, culminating in 2016, the results obtained for each phase fell short of those forecasted (Table 3). The financial restraints policies implemented between 2011 and 2014 due to the intervention by the Troika [36,37] was one of the reasons that contributed to limited RNCCI growth. Nevertheless, the expenditures in the RNCCI increased both as a share of the GDP and as a share of current health care expenditures (Table 2). Other reasons for limited RNCCI growth are related to insufficient revenue from social gambling to finance the RNCCI [38] and a lack of public resources to fund signed-protocols between the state and third sector entities.

4. Current challenges and ongoing developments

The universal access, the multiple sources of financing, the existence of several NH to account for different care needs or the sustained increase of admissions in both settings of LTC, are considered to be some of the RNCCI achievements (Box 1). On the opposite side, the predominance of institutionalization, the existence of waiting lists, regional asymmetries, the absence of a financing model based on the dependence levels, or the difficulty to use the instrument of needs assessment for international comparison, are some of the aspects to be improved in the future.

Several measures have been implemented which target the main challenges for LTC. First, there is an ongoing joint project between the MoH and the MLSS called Programme of Integrated Support to the Elderly (*Programa de Apoio Integrado a Idosos*), which has enabled the development of initiatives in both health and social areas oriented for home care and informal caregivers as part of a job creation policy [40]. However, given the scarcity of formal HCBS responses, it remains essential to reinforce primary care providers with human and material resources to target risk groups living in the community and develop initiatives aimed at maintaining the

Table 3
Difference between the number of "forecasted" and "real" beds in each stage.

	Stage I (2006–2008) Forecasted (Real*)		Stage II (2009–20012) Forecasted (Real**)		Stage III (2013–20016) Forecasted (Real***)	
NH Units	Number beds	Beds/1000 inhab. aged ≥ 65 years	Number beds	Beds/1000 inhab. aged ≥ 65 years	Number beds	Beds/1000 inhab. aged ≥ 65 years
UC	977 (530)	0.60 (0.32)	1,954 (867)	1.20 (0.44)	2,931 (811)	1.80 (0.39)
UMDR	1,139 (922)	0.70 (0.56)	2,117 (1820)	1.30 (0.93)	3,257 (2578)	2.00 (1.24)
ULDM	2,720 (1325)	1.67 (0.81)	5,374 (3031)	3.30 (1.55)	8,143 (4723)	5.00 (2.27)
UCP	326 (93)	0.20 (0.06)	651 (193)	0.40 (0.10)	977 (288)	0.60 (0.14)
HCBS (number of teams)	363 (72)	–	363 (243)	–	363 (279)	–

Source: Authors elaboration based on the national reports [30,32,34,39].
* Values of 2008.
** Values of 2012.
*** Values of 2016; UC: Convalescence Units; UCP: Palliative Care Units; UMDR: Medium Term and Rehabilitation Units; ULDM: Long-Term and Maintenance Units; HCBS: Home and Community-Based Services.

Box 1: Strengths and weaknesses associated to the RNCCI.

Strengths

- Filled a gap in the National Health Service;
- Universal coverage to long-term care;
- Multiple sources of financing;
- Different nursing homes types to account for different care needs;
- Sustained increase of referrals and admissions to the RNCCI;
- The existence of an autonomous National Network of Palliative Care;
- Free beds in the hospital setting.

Weaknesses

- Predominance of institutionalization over home care;
- Regional asymmetries in the provision of care;
- Financing model based on the number days of care provided;
- No consequences for non-compliance with the expected length of care defined for each type of nursing home, what contributes to increase costs and waiting lists;
- The instrument used to assess the dependence level does not allow a complete evaluation of each individual, limiting any benchmarking analysis between settings of care.

autonomy of the elderly in their usual living environment. Besides, other approaches such as the initiative by the recent report of the European Forum for Primary Care, could be consider, which entails the creation of multidisciplinary teams (physicians, nurses, pharmacists and social workers), responsible for the implementation of a proactive geriatric assessment of individual medical, functional and social needs [41].

Secondly, given the importance to collect accurate information for each patient, an Ordinance was recently published [42] which demands a more complete patient assessment before referral to the RNCCI. The identification of all comorbidities, a detailed medical, nursing and social evaluations, as well as the assessment of the function degree using the International Classification of Functioning, Disability and Health is required [43]. Nevertheless, it is key to underline the importance of collecting relevant data to inform the design of a patient's care plan. Furthermore, adopting international validated metrics for monitoring the quality of the care provided and for benchmarking between similar LTC settings is of paramount importance.

Third, given the role of informal care [2], in 2016 the MoH published a Dispatch creating the National Programme for Health, Literacy and Self-care (*Programa Nacional para a Saúde, Literacia e Autocuidados*) with the purpose of creating a structured network of informal caregivers [44]. Thus, projects developed under this Programme should aim at the reinforcement of the citizens' role in the NHS through partnerships between several players, to prevent social exclusion and develop and share techniques for promoting health literacy in both NH and HCBS settings, for both caregivers and dependent individuals.

Finally, a change in the financing model included patients' dependence levels and risk adjustment models and removed existing incentives to unnecessary care and bed occupancy of people who no longer need care. This change might not only improve the bed/treatment places turnover, but could also help to tackle existing waiting lists. Although there are no plans or deadlines for implementing these measures, some policy-makers from the MoH have publicly stated that policies to tackle this area are vital to ensure the efficiency and growth of LTC in Portugal in the future [45].

5. Conclusions

In 2006, driven by policies to vertically integrate the provision of all types of care within the NHS, the RNCCI was set up to take advantage of already existence resources (largely non-profit-making institutions). Its main sources of funding was shared by the MoH and the MLSS. This is the first study that collects monitoring data on the evolution of the LTC in Portugal since its inception, making it available to an international audience by providing an assessment of the current state of the RNCCI and guidance on existing challenges and gaps for Portuguese policy-makers.

Based on the organisation of the LTC model of Catalonia, the RNCCI is coordinated by central, regional and local entities, similar to other EU countries such as Spain, Italy and Sweden. The RNCCI provision of in-kind services is much higher than the EU average, while the provision of cash-benefits is minimal. Co-payments are means tested and update yearly. The financial constraints over public spending in place since 2011 have also contributed to a slower development of the national network. Despite public LTC expenditures as a share of the GDP increasing in the same period, further efforts should focus on improving the efficiency and accessibility of the LTC system in Portugal.

Conflict of interest statement

Nothing to declare.

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